

The imperative for hospital-based palliative care: patient, institutional, and societal benefits

ROBERT L. FINE, MD

Challenges in societal demographics, finances, and human suffering are pushing us towards a new paradigm in health care delivery. The palliative care paradigm is a necessary complement to existing acute care and chronic care paradigms. Palliative care does not replace prior paradigms; instead, it adds value and provides a shift in focus when appropriate. Baylor University Medical Center has all of the components needed for an effective palliative care program, including expertise in palliative medicine, pain management, ethics, geriatrics, oncology, other medical specialties, nursing, social work, and pastoral care. The palliative care consultation service will enhance patient care and improve financial performance in patients with serious life-limiting illnesses.

CASE STUDY: BAYLOR'S FIRST PALLIATIVE CARE CONSULTATION

A 49-year-old woman had widely metastatic ovarian cancer with a palliative diverting colostomy, progressive renal failure, diabetes mellitus, hypertension, an open abdominal abscess, and respiratory insufficiency associated with morbid obesity (body weight of 450 pounds). She had stopped eating effectively and was both hypoalbuminemic and anemic. She was dependent for 5 of 6 activities of daily living, was bed bound, and had multiple areas of skin breakdown. Her physicians understood her limited life expectancy and had been attempting to discuss do not resuscitate orders and possible hospice evaluation. The patient and family, however, insisted that "everything be done," including cardiopulmonary resuscitation. The attending physician requested an ethics consult but agreed instead to a new type of consult available at Baylor University Medical Center (BUMC), a palliative care consult.

At the time of palliative care consultation, the patient had been hospitalized for 25 days, and this was her second hospitalization in about 4 months. She was being cared for on a general ward with intravenous antibiotics, wound care, physical therapy, and propoxyphene plus acetaminophen (Darvocet) for pain. When first seen by the palliative care team, the patient denied pain even though she appeared to be in obvious distress with frequent moaning and crying out. She then confessed that her pain varied between 6 and 8 on a 10-point scale, but she did not admit this to the doctors or nurses because she was afraid they would give her a shot that would stop her breathing and make her "suffocate." (She had experienced respiratory depression when given meperidine earlier during hospitalization.)

A multidisciplinary team consisting of a specially trained physician, nurse, pharmacist, social worker, and chaplain began work with the patient, her family, and staff. Within 48 hours of

consultation, the palliative care team was able to achieve several important goals:

1. The patient worked through her denial, accepted that she was dying, and accepted palliative care as the primary goal of therapy (something other physicians had not persuaded her about even though she had been in the hospital for over 3 weeks).
2. She agreed to a do not resuscitate order.
3. She was able to express a wish that she die at home in her own bed if possible.
4. She accepted recommendations for improved pain control and agreed to report her symptoms accurately. She was reassured that she would not be "put to sleep" with pain medicines and that she could choose to accept or reject them. Her pain medications were adjusted for her severity of pain as well as for her progressive anuric renal failure. Although she initially refused some pain medications, she began to ask for and accept those medications as her pain got worse. As a result, her pain declined from an average of 7 to 0 on a 10-point scale.
5. She asked for help in communicating with her family members, who were in considerable denial. This proved to be the most challenging aspect of her case.
6. Multiple expensive and ultimately nonbeneficial medications were discontinued.
7. The patient requested spiritual comfort through baptism, which was arranged in a bedside service.
8. Although family members continued to experience significant denial, the palliative care team supported them as well as the entire staff and the patient was eventually admitted to an inpatient hospice. (It was felt that her care could not be adequately managed at home.)

BUMC has previously addressed complex issues near the end of life through one of the oldest ethics consultation services in the country as well as through hospice services. Beginning in April 2004, BUMC is now able to offer a new method of addressing complex physical symptoms, psychosocial problems, and spiritual issues in the setting of life-limiting or terminal illness. The palliative care service was developed in response to societal challenges

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Corresponding author: Robert L. Fine, MD, 3434 Swiss Avenue, Suite 300, Dallas, Texas 75204 (e-mail: rl.fine@BaylorHealth.edu).

and the desire to better serve our patients. This article reviews those challenges and describes what palliative care is and how palliative care consultation has been implemented at BUMC.

SOCIETAL CHALLENGES

The demographic challenge

Health care delivery is being affected by several societal challenges. With an aging population, the number of patients with chronic illnesses has been growing steadily. In 2000, 122 million people had chronic illnesses; the numbers are projected to be 132 million in 2005, 140 million in 2010, and >170 million in 2030. In any given year, most patients with chronic illnesses live; however, in the USA approximately 2.4 million persons die each year, with 90% of those deaths occurring in the course of a chronic illness (yearly death rate, 0.85%). This includes 150,000 deaths in Texas (yearly death rate, 0.71%) and 1700 deaths at BUMC (yearly death rate, 4.5%). Data on the number of patients who die at home or in nursing homes within 6 months of leaving BUMC are not readily available.

Among Medicare patients, 98% spend at least some time in a hospital during their last year of life. Although 70% of patients say they would like to die at home, approximately 50% die in a hospital and 25% in a nursing home. Approximately 20% of terminally ill patients die following admission to the intensive care unit (ICU). Only 25% of patients die under the care of a hospice or by palliative care services. Thus, 75% of dying patients are not served by the only branches of organized medicine with specific expertise in end-of-life care. We would be shocked if general surgeons rather than thoracic surgeons provided 75% of the bypass surgery in this country!

The demand for life-sustaining treatments can seem unlimited, as few patients are truly ready to die when confronted with a terminal illness. Life-sustaining treatments are often quite effective and may even seem to border on the miraculous. At other times, however, life-sustaining treatments keep patients alive for long periods of time without necessarily making them well. Occasionally we see patients receiving multiple life-sustaining treatments: left ventricular assist devices, implantable defibrillators, ventilators, dialysis, feeding tubes, pressors, and so on. These patients are frequently too ill to survive outside of the ICU, and yet with so many organ systems supported, how can the patient die? Thoughtful persons may legitimately ask whether we are prolonging life or prolonging dying. In circumstances of prolonged dying, the quality of life the patient can achieve with aggressive life-sustaining treatments is very poor. In addition, the resources to provide these treatments are finite both at a societal level and at a hospital level.

The financial challenge

The issue of how much of our financial resources should be spent on health care is an important societal challenge. While national health care costs dipped in the early 1990s, they are now climbing rapidly again (Figure 1). Thirty percent of Medicare costs cover care for the sickest 5% of patients, and 70% of overall health care costs cover care for the sickest 10% of the population. Of the \$242 billion in Medicare expenditures in

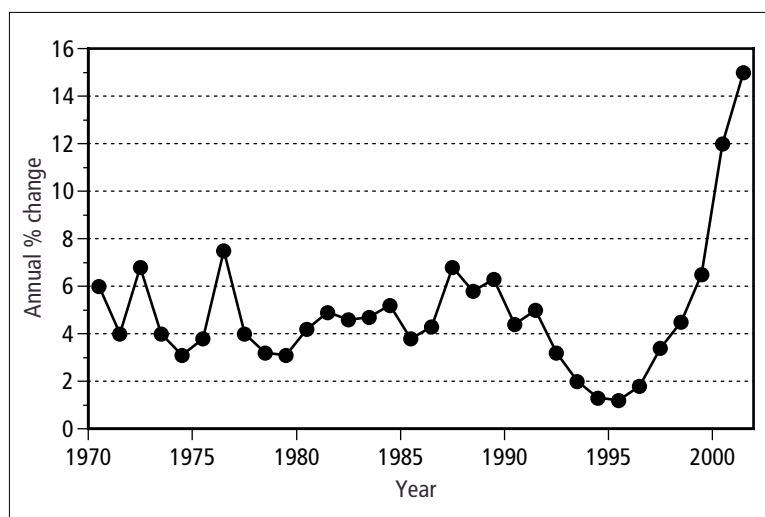


Figure 1. Growth in expenditures for health care in the USA, 1970–2003. Source: Health Care Financing Administration, Office of the Actuary, National Health Statistics Group, 2003.

2001, 26%, or \$63 billion, was spent during the last 12 months of life, and 14%, or \$34 billion, was spent in the last 2 months of life. While it can be difficult for physicians to recognize when a patient has reached the last 12 months of life, it should be easier to tell when a patient is approaching his or her last 2 months of life, and aggressive financial expenditures might reasonably be reconsidered. Spending more money does not necessarily lead to improved results. Researchers at Dartmouth Medical School demonstrated that some regions of the country spend 1.6 times more money per Medicare patient than other parts of the country, yet the increased spending does not lead to better quality of care or longer life (1).

Finally, individuals and families are affected by the cost of care as well. Personal expenditures on medical care are the major cause of personal bankruptcy. Physicians, nurses, and other health care providers generally have enough personal resources to meet their own health care needs. This may cause them to lose sight of the fact that more than half of the elderly population has an income of <\$20,000 and spends >25% of it on health care (2).

The human suffering challenge

Health care providers would like to think that they make their terminally ill patients as comfortable as possible. However, human suffering remains very significant. Among 9000 patients treated at 5 major teaching hospitals that participated in the SUPPORT study (3, 4), 43% of patients with congestive heart failure and 60% of patients with colon cancer reported moderate to severe pain at 8 to 12 days of hospitalization. Further, >50% of patients had serious pain the last 3 days of life. It might be understandable that critically ill patients on admission to a hospital have severe pain, but how can we justify such circumstances after the patient has been in the hospital for a week, let alone when the patient is within 3 days of death? Must we truly suffer our way to death? Is that what we want for ourselves when our time comes? The SUPPORT study showed poor communication between doctors and patients about goals of care and substantial emotional suffering among patients, families, and professionals. The study also confirmed the financial burdens of serious illness, as 31% of patients' families lost most of their life savings.

THE IMPERATIVE FOR PALLIATIVE CARE

The demographic, financial, and human suffering challenges create an imperative for a new model of bringing real care to the most seriously ill patients we serve. Health care providers can fall into the trap of using every technology on every patient because it is available or because the patient asks for it. Instead, we must determine when the physical, psychological, and financial burdens outweigh the benefits of life-sustaining treatments. Philosophies of treatment and systems of care are needed that remove the false dichotomy of “doing everything” vs “doing nothing.” When the burdens of treatment outweigh the benefits, following the palliative care imperative has the potential to provide a more beneficial service than the technological imperative.

Palliative care and the demographic challenge

For better or worse, the palliative care population is a growing market, and palliative care consultation services will ultimately be quite busy. Not only are there currently over 120 million patients with chronic illnesses, but we have not yet seen the influx of Baby Boomers into this group. In 2000, there were 79 million Baby Boomers (this author being one of them). In 2031, when the first Baby Boomer turns 85, 51 million Baby Boomers will remain. At current life expectancies, the last Baby Boomer should die around the year 2070. As the Baby Boomers age and approach death themselves, we can expect the demand for palliative care services to grow.

Palliative care and the financial challenge to reduce costs

Palliative care has been shown to reduce direct costs for both hospitals and payers. Mount Sinai Hospital saved \$757,555 in 1 year by implementing its palliative care service for patients who had been in the hospital 2 weeks or more (5). Kaiser Permanente conducted a retrospective review of costs for patients who died on usual care vs those who died on palliative care and found a \$6580 reduction per patient on palliative care (6). At the University of Michigan, palliative care in patients with advanced cancer who met hospice criteria but were not enrolled in hospice reduced costs from \$13,126 to \$8,974 with shorter hospital length of stay and fewer visits to the emergency department. In addition, those in the palliative care group lived longer than those in the usual care group: 266 days vs 227 days (6). This study is one of the first to confirm the anecdotal impression among some palliative care providers that when terminally ill patients' symptoms are better treated, they may live longer. At Virginia Commonwealth University, patients who died on the palliative care unit had expenditures that were 66% less than those of patients who received usual care (7). Other studies have also confirmed a financial benefit to palliative care interventions (8–14).

We have been providing what we refer to as clinical ethics consultations at BUMC since 1985. Most of those consultations deal with patients near the end of life and in many ways are quite similar to palliative care consults. In 2002, BUMC saw a 50% reduction in direct patient care costs following ethics consultations dealing with end-of-life issues (Figure 2). In addition, we believe that implementation of the futility of care dispute resolution process in 1999 may have saved nearly \$6 million of hospital charges in 1 year. We further believe that if the ethics consult had been optimally timed—i.e., after the first physician recognized

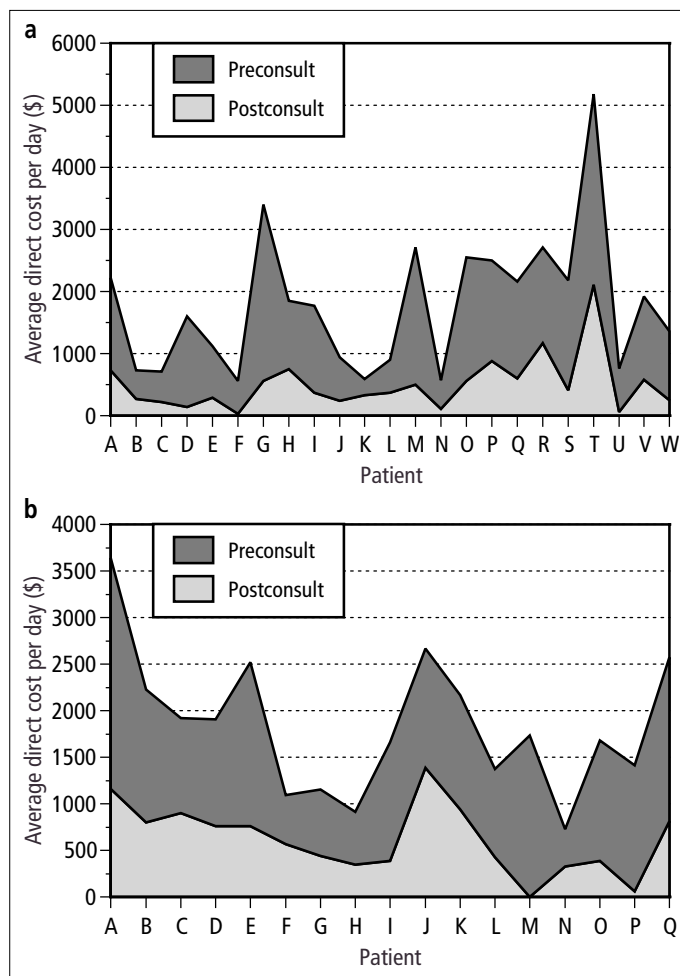


Figure 2. The cost of care per day before and after end-of-life ethics consultation at Baylor University Medical Center in 2002. The cost after consultation was only half that before consultation in two groups: (a) patients with a length of stay of 0 to 13 days, and (b) patients with a length of stay of 14 to 30 days.

that care was futile, rather than waiting for consensus of a group of providers—an additional \$3 million might have been saved. Based upon our experience with clinical ethics consultation as well as data published in the literature, we conservatively estimate that palliative care consultation may reduce direct costs of care for terminally ill patients at BUMC by at least 25% while also helping to improve hospital capacity and coordinate the most appropriate treatment and care.

Palliative care and the challenge to reduce human suffering

As with the case consultation at the beginning of this article, data demonstrate that palliative care relieves pain and distressing symptoms, supports ongoing reevaluation of goals of care and difficult decision making, improves quality of life, improves satisfaction for patients and their families, eases burdens on providers and caregivers, and improves transition management (15–27).

As an example of the published data, Mount Sinai Hospital evaluated the level of pain, nausea, and dyspnea in 2219 patients treated on its palliative care consult service between 1997 and 2002. Whether symptoms were originally severe, moderate, or mild, they improved significantly between the patient's initial evaluation and final evaluation (4).

WHAT IS PALLIATIVE CARE?

Palliative care is multidisciplinary care that aims to relieve suffering and improve the quality of life for patients with advanced life-limiting illnesses. This suffering is not only physical but may also be psychological, spiritual, or social. Palliative care focuses on supporting not only the patient but also the patient's family and the primary treatment team.

Frequently, both providers and patients think in terms of a cure-or-care dichotomy in which we either pursue a life-prolonging cure or switch to death-affirming palliative/hospice care. The transition between the two approaches is often abrupt and unpleasant for all. Instead, palliative care may be offered simultaneously with all other appropriate medical treatment as an add-on service. As a serious illness is diagnosed, symptoms should be fairly easy to manage, but as the disease progresses, symptom burden rises and patients need more and more palliative care services. As Eric Cassell stated:

The relief of suffering and the cure of disease must be seen as twin obligations of a medical profession that is truly dedicated to the care of the sick. Physicians' failure to understand the nature of suffering can result in medical intervention that (though technically adequate) not only fails to relieve suffering but becomes a source of suffering itself (28).

It is helpful to clarify what palliative care is and what it is not (Table 1). Palliative care differs from ethics consultation in its goals and processes. While the goal of palliative care is to relieve suffering among patients with life-limiting or terminal illnesses, the goal of ethics consultation is to resolve ethical uncertainties and communication problems. Palliative care specialists can write orders in the patients' charts and charge for services, while ethics consultants do neither. In that sense, palliative care consultants are like any other medical consultant. Their approach nevertheless differs from that of pain management consultants (who at BUMC are primarily procedurally focused) and from that of geriatric consultants (who work with all patients who are frail and elderly).

Palliative care also differs from hospice. While the goals of the two are the same, to be eligible for hospice care, a patient must acknowledge his or her terminal illness and stop aggressive life-sustaining treatment. Those requirements do not apply to palliative care. Hospice is a specific Medicare benefit and often a specific benefit of various insurance plans that have differing conditions for enrollment. Palliative care is not a specific Medicare or other insurance benefit, but it can become a bridge to hospice, allowing patients to think in terms of symptom relief earlier and to adapt to the idea.

Palliative care is appropriate for all life-limiting diseases, not just cancer. In fact, 77% of deaths are not due to cancer. We are defining a life-limiting illness as one from which the patient is expected to die, although not necessarily within the classic 6-month timeframe of a terminal illness, and which often has significant troubling symptoms that impair the patient's quality of life and place a significant burden on caregivers. Typically we think of patients with life-limiting illnesses as being in the last 1 to 2 years of life. Common chronic life-limiting illnesses are heart disease, causing 33% of deaths; malignant neoplasm, 23%; cerebrovascular disease, 7%; chronic obstructive pulmonary disease, 5%; diabetes, 3%; renal diseases, 2%; and dementia, 2% (29).

Table 1. Explanation of palliative care

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|--|--|
| Palliative care is | |
| <ul style="list-style-type: none">• Expert care of pain and symptoms throughout illness• Communication and support for decision making, including advance care planning• Attention to practical support and continuity across settings• Care that patients want at the same time as efforts to cure or prolong life• Care that can ease the transition from life to death even if the patient does not choose hospice care | |
| Palliative care is not | |
| <ul style="list-style-type: none">• "Giving up" on patients• What we do when there is "nothing more that we can do"• In place of curative or life-sustaining treatment—although when life-sustaining treatment is no longer appropriate, it is a good alternative to "doing nothing"• The same as hospice | |

Desires of patients and their caregivers

Palliative care is more than a response to demographic and financial challenges. Clearly, palliative care is a response to the desires of both patients and their caregivers. A JAMA study of 126 patients who had renal failure or HIV or who resided in a long-term care facility listed their goals of care. First on the list was controlling pain and symptoms, followed by avoiding inappropriate prolongation of the dying process, achieving a sense of control, relieving burdens on family, and strengthening relationships with loved ones (30). In another study in which 340 seriously ill patients were asked to rank 44 attributes of quality of treatment near the end of life, they selected the following attributes as most important: freedom from pain, peace with God, presence of family, mental awareness, honoring of treatment choices, orderly finances, belief that life was meaningful, resolution of conflicts, and the ability to die at home (31). Most physicians do not address patient goals such as being at peace with God. However, the palliative care consultation service includes pastoral care representatives, as well as social workers, nurses, and physicians who are better trained to address all of the concerns of patients, including spiritual concerns.

Family caregivers had specific goals as well. As reported in Tolle's study involving 475 family members 1 to 2 years after bereavement, they wanted their loved ones' wishes honored, as well as inclusion in the decision process; support and assistance at home; practical help with transportation, medicines, and equipment; the ability to attend to personal care needs (bathing, feeding, toileting); honest information; continuous access to caregivers; a sense that they were being listened to; privacy; and contact after the death (32).

To a large extent, the acute care and chronic care models are not delivering what patients want. The palliative care model can do better.

National trends in palliative care

Regulations of the Joint Commission on Accreditation of Healthcare Organizations encourage palliative care, and *US News & World Report* will begin ranking hospitals in the category of

Table 2. Services offered by the palliative care consultation service at Baylor University Medical Center

- Assistance in managing complex physical symptoms such as pain, nausea, or dyspnea
- Assistance in managing complex psychosocial issues, including depression, grief, and anxiety
- Emotional, psychological, and spiritual support to patients, families, and staff
- Counseling related to prognosis and decisions near the end of life
- Assistance with advance care planning
- Liaison between the hospital and other care sites such as hospice/home care
- Grief counseling and bereavement support
- Auditing, research, and training

palliative care services. As of 2002, according to the American Hospital Association, 17% of community hospitals and 26% of academic teaching hospitals had a palliative care consultation service or inpatient unit. A formal palliative care consultation service has another advantage: it can offer a regular teaching rotation in end-of-life issues, thus remedying some deficiencies in US medical training programs. In 1997, Billings and Block at Harvard reported that 74% of residencies offered no training in end-of-life care, 83% of residencies offered no hospice rotation, 41% of medical students never witnessed an attending talking with a dying patient or his family, and 35% of medical students never discussed the care of a dying patient with a teaching attending (33). Since all patients (and all providers) eventually die, it is essential that physicians be well prepared to lead patients through this transition from life to death. How we care for our patients now will greatly impact how we are cared for when we are faced with our own mortality.

THE PALLIATIVE CARE CONSULTATION SERVICE AT BUMC

The palliative care consultation service at BUMC began in April 2004 with a multidisciplinary team consisting of a core group of trained physicians, nurses, chaplains, social workers, and pharmacists. The medical director is Robert Fine, MD, who is board certified in palliative care. Assistant directors are Roberto de La Cruz, MD, and Mark Casanova, MD. Currently, 5 physicians are trained to provide the service, and ultimately 10 to 12 will be. Our goal is for all to become board certified.

The palliative care team will meet weekly and will coordinate results with the attending physician and other consulting physicians for each patient. The team is available to see patients on any unit in the hospital; they will be able to write orders and actively manage palliative care issues with the approval of the attending physician. At some point, an inpatient unit for palliative care may be developed. No outpatient activity is planned.

It is important to note that physicians can request a palliative care consult even if they do not need specific medical consultation, i.e., the services of a physician. They may feel comfortable handling pain and symptom management—particularly with the use of pain management protocols as they become available—but may seek assistance in psychosocial issues for which they may not

have the time or expertise. Members of the team will be able to provide a variety of services (*Table 2*).

SUMMARY

Palliative care is a universal health professional obligation that improves the quality, service, and efficiency of care for our sickest and most vulnerable patients and families. Palliative care supports physicians, nurses, and the multidisciplinary team, complementing existing services. It improves financial performance and resource allocation for the hospital and supports stewardship of societal resources. We believe the palliative care consultation service at BUMC represents a continued beneficial paradigm shift for all patients and staff.

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